California Department of Health Services

Home and Community-Based Services Branch

In-Home Operations (IHO) Section

Summary of the November 16, 2006,

Stakeholders Meeting

Discussion of the Restructuring of the IHO Home and Community-Based Services Waivers

Stakeholders' Meeting to Discuss Restructuring
In-Home Operations (IHO) Waivers
November 16, 2006
2:00-4:00 p.m.

Meeting Summary

I. Purpose of the Meeting

The purpose of the meeting was to provide a forum for stakeholder input into the structure and operation of the Nursing Facility Acute Hospital (NF/AH) Home and Community-Based Services (HCBS) Waiver program. This will be the first in a series of meetings.

II. Overview of the In-Home Operations Waiver Program

In-Home Operations (IHO) currently administers three HCBS waivers, which are designed to offer safe and appropriate home care to individuals in lieu of long-term institutional placement.

The In-Home Medical Care (IHMC) Waiver was established in the early 1980's. In 2002, the Nursing Facility A and B Level of Care (NF A/B) was created as a renewal of the former NF Waiver, the NF Subacute (NF SA) Waiver was created as a new waiver and the Model NF Waiver was terminated. The beneficiaries from the NF and Model NF Waivers were transitioned to either the NF A/B or the NF SA Waiver based upon the beneficiaries assessed level of care.

The IHMC Waiver

Offers services to persons with physical disabilities who:

- would otherwise require acute care for a minimum of 90 consecutive days;
- have a catastrophic illness or injury; and
- are dependent on medical technology to replace or supplant major organ systems.

Waiver Capacity:	300 slots.
Number of Filled Slots:	66
Number on Wait List:	0

The NF SA Waiver

Offers services to persons with physical disabilities who:

- would otherwise require adult or pediatric subacute nursing facility care for a minimum of 180 consecutive days;
- have a significant illness or injury; and
- may or may not be dependent upon some medical technology to supplant or assist major organ function.

Waiver Capacity: 905 slots.
Number of Filled Slots: 635
Number on Wait List: 0

The NF A/B Waiver

Offers services to persons with physical disabilities who:

- would otherwise require intermediate nursing facility (Level A) or skilled nursing facility (Level B) care for a minimum of 365 consecutive days;
- require assistance with personal care; and/or
- have some skilled nursing care needs.

Waiver Capacity: 890 slots.
Number of Filled Slots: 890
Number on Wait List: 650

Services provided:

- Case Management
- Transitional Case Management (can begin 180 days prior to discharge)
- Private Duty Nursing
- Shared Private Duty Nursing
- Environmental Accessibility Adaptations
- Personal Emergency Response Systems
- Personal Care Services (Companion and Attendant Care)
- Family Training
- Utility Coverage

III. Current IHO Waiver Status

Nursing Facility and Acute Hospital (NF/AH) Waiver

The Department has combined the IHMC, NF SA, and NF A/B Waiver into one waiver: the NF/AH Waiver.

The NF/AH Waiver includes:

- all the services and provider types of the previous three waivers;

- an additional 500 slots for the NF A and B level of care, 250 of which are reserved for individuals who are residing in a nursing facility and would like to return to their home and community; and
- two new services – Habilitation and Community Transition.

The addition of the 500 slots and the two new services are in compliance with Welfare and Institutions Code 14132.99.

In-Home Operations (IHO) Waiver

During the development of the NF/AH Waiver, CMS advised the Department that a second 1915(c) HCBS model waiver should be developed to serve individuals who have been continuously enrolled in one of IHO's HCBS waivers prior to June 1, 2002, and are primarily receiving waiver private duty nursing services from licensed nurses.

IHO has developed a model waiver, titled the IHO Waiver, which includes all the same services and provider types in the IHMC, NF SA, and NF A/B Waivers and has added Habilitation services.

Beneficiaries currently enrolled in the IHMC, NF SA, and NF A/B Waivers will be transitioned to either the NF/AH or IHO Waiver. This transition will occur without any break in their authorized waiver services.

Both waivers were submitted to CMS on September 29, 2006, and are now in the 90-day review period.

IV. Discussion Topics

Stakeholder input on the various discussion topics is listed below.

Current/Future Waiver Capacity

- Develop a process to accurately project the need for waiver services.
- Build into the waiver the ability to increase the number of waiver slots to reflect an accurately projected need for waiver services.
- Amend the waiver in expectation of increased need due to the "Money Follows the Person" grant.

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- Transfer unused slots from one level of care to an underserved level of care, i.e. transfer unused slots from the IHMC level of care to the NF A/B level of care.

- Provide a geographic distribution of available waiver slots so one area of the state does not monopolize a majority of the available slots.

- Establish a timeline as to when the Department will increase the number of individuals who can be served to be more reflective of the number of individuals who want to remain in or return to their home and community.

- Information on the HCBS waivers needs to be presented to individuals and their families in a manner that they understand. Information needs to be in multiple languages and formats for the hearing and visually impaired.

- Hospital and nursing facility discharge planners need to be educated on the availability of the HCBS waivers.

- Provide waiver services based upon the needs of the participant and not based upon the individual's cost cap.

Individual Cost Neutrality Caps

- Amend the NF/AH Waiver to reflect the current cost Medi-Cal incurs for nursing facility care.

- Modify the waiver's cost neutrality to allow for an increase in In-Home Supportive Services (IHSS) Personal Care Services (PCS) reimbursement rates without the need to reduce currently authorized waiver services to obtain cost neutrality.

- Consider changing the cost neutrality methodology from the individual to the aggregate.

- A waiver participant must sometimes choose between supplies and direct care services.

- Determine the average annual increase in the IHSS rate and withhold that amount from expenditures for waiver services. This will allow the participant to retain authorized services when IHSS rates are increased.

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Administration of Waiver: State vs Local Approach

- Explore local administration of the waivers. It may facilitate outreach and the participant's access to HCBS administrative personnel.
- Develop a "single-point of entry" for programs that assist the elderly and/or disabled.
- Utilize the Multi-purpose Senior Services Program (MSSP) Waiver model to allow for the design of the services to reflect the services and provider types that are available in the community.
- Be aware of resource differences in counties, some counties are rich in providers and resources, and some counties have very limited or no providers or resources.
- Standardize enrollment assessment criteria and processes.
- Look at what works and what does not work with locally administered waiver programs.
- Will a locally administered waiver program serve a greater number of participants?

Other Services, Issues to Consider

- The Department should address the requirement to pay for services provided by waiver personal care service (WPCS) providers twice a month.
- Ensure WPCS providers are paid timely.
- There is a need to increase WPCS wages and include benefits.
- Schedule stakeholder meetings in other locations in the State to allow all interested parties to attend in person.
- Address the lack of providers available to provide requested services
- Increase the Medi-Cal reimbursement rate for HCBS waiver services.
- Establish a working relationship with Supportive Living Services agencies to provide services to HCBS waiver participants.

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- There is a need for a Traumatic Brain Injury (TBI) HCBS waiver to meet the unique needs of individuals who suffered from a TBI.

- The NF/AH Waiver's Quality Assurance process should include a person-centered participant satisfaction survey that addresses the participant's qualify of life issues.

Next Steps

- Schedule a follow-up meeting for the end of January or in February to discuss possible solutions to identified issues, identify any barriers, and begin to develop a plan of action.

- The Department will address the issue of bi-monthly payments for waiver personal care services.

- Provide an e-mail address for stakeholders to submit written questions and comments: IHOWaiver@dhs.ca.gov .

- Post a summary of the issues discussed at this meeting and stakeholder written comments on the IHO Waiver website: www.dhs.ca.gov/ihos .

California Department of Health Services

Home and Community-Based Services Branch

In-Home Operations (IHO) Section

Stakeholders Written Comments Regarding the Restructuring of the IHO Home and Community-Based Services Waivers

DATE: November 16, 2006

FROM: Melinda Cochran
TO: California Department of Health Services
RE: In Home Operations (IHO)
ATTN: Sarah Steenhausen, Deborah Doctor, et al.

I am writing concerning the In-Home Operations Waiver service. I would like to tell you why the program is so important in my life.

A little about myself:
I believe I was one of the first people on the waiver in the San Francisco Bay area. I am totally paralyzed due to progressive multiple sclerosis; however, I can still use my voice. Even though I am paralyzed, I have been determined to live an independent life. Due to the assistance of the State of Californiia Health Services Department and IHO, I have been able to transition from my previous profession as a school teacher/librarian, to my current endeavor as a California Marriage and Family Therapist.

Before the waiver I was always staying at home because I did not have support. But for the last three years I have been able to attend community events such as church, opera, museums, and visiting friends.

The IHO waiver has provided me the means and resources to hire assistants. One good example is that these assistants have facilitated my use of the computer. I am now able (without assistance) to open and close my front door, pay my bills online, contact family and friends (e-mail), take online classes (for example continuing education classes required by my license). For years I had gone without television or listening much to music. But now, via computer technology I can control the television and the stereo by myself.

The people that I've been able to hire have given me the ability to develop a life that is filled with interesting challenges and adventures.

In-Home Health Operations has been in partnership with me, assisting me to develop my life productively and independently, contributing and participating in the larger community. I continue to have an optimistic outlook on living... in no small part because the waiver has contributed to my improved physical and mental well-being.

What restructuring/improvement of in-home health operations would I propose?

One idea I would suggest is that there be an open meeting of all IHO consumers and staff (in our geographic area) so that we can together discuss issues and alternatives to services.

Currently I only see a representative of IHO once or maybe twice a year, and then only in private.... I have no direct connection with my peers (other IHO consumers). I want to be educated by others -- consumers, staff -- about their experiences, that I might improve my life; and also, in sharing my experiences, I would hope to help others.

I believe an open meeting would help educate the consumers and the staff about new possibilities.

In short the financial support provided provide by In-Home Operations has made my life markedly better! It is so important to persons like me who wish to live outside of larger institutional settings such as nursing homes.

Sincerely yours,
Melinda Cochran. MA

PAI Protection & Advocacy Inc.

Advancing the rights of Californians with disabilities

OAKLAND REGIONAL OFFICE
1330 Broadway, Suite 500
Oakland, CA 94612
Tel: (510) 267-1200
TTY: (800) 649-0154
Toll Free: (800) 776-5746
Fax: (510) 267-1201
www.pai-ca.org

November 14, 2006

Sarah Steenhausen
California Health and Human Services Agency
1600 9th Street, Suite 460
Sacramento, CA 95819

RE: Position Statement Regarding HCBS Waivers

Dear Sarah:

Protection and Advocacy, Inc. (PAI), a non-profit advocacy agency mandated to advance the human and legal rights of persons with disabilities, has worked closely for many years with Californians with disabilities (including seniors) who wish to avoid or leave long term care institutions. Waivers are potentially an important tool for those consumers, yet the shortcomings of the current nursing facility waivers limit their usefulness. We are submitting this document as PAI's formal input to the Waiver Stakeholder process.

First, in light of the importance of the waivers, PAI requests that the California Health and Human Services Agency make the stakeholder process fully accessible to consumers by:

- Holding additional stakeholder meetings in different areas of the State; and
- Providing support to consumers to facilitate their attendance and full participation.

While the NF A/H Waiver application submitted to CMS on September 29, 2006 will make some important changes to the Nursing Facility A/B and Subacute Waivers, other fundamental changes must be made to enable a meaningful number of Californians with disabilities to leave or avoid institutional placement. We believe that the State is **obligated** to make such changes to comply with the U.S

Supreme Court's *Olmstead* decision.

Changes critical to making the Waivers more effective include:

1. INCREASE THE NUMBER OF SLOTS: Expand the NF A/B Waiver to reflect the number of people in California who are in nursing facilities. Approximately 100,000 people live in nursing facilities in this State on any given day. Many measures show that a large percentage of them would prefer to get out and live in their homes or in the community. A Waiver with only 1,240 slots is shamefully insufficient; the State should use real estimates of the need for Waiver slots and make many more available.

   Recommendation: PAI strongly recommends that the State use available sources of information to project the need for Waiver slots and use such information to expand the Waiver commensurate with need in the State. The HCBS Waiver for individuals with developmental disabilities has approximately 70,000 slots for a population of 200,000 consumers. In comparison, a NF A/B Waiver with 1240 slots for a population of at least 100,000 nursing facility residents is woefully inadequate. Expanding the Waiver by tiny increments, as is done now, rather than a comprehensive assessment of projected need is simply wrong.

   Rather, the State should extrapolate from one or more of at least five sources of reliable, current data;

   - the Sonoma and Westside Independent Living Center projects;
   - the UCLA Money Follows the Person project;
   - MDS data; and
   - San Francisco's Targeted Case Management (TCM) Program.

   These sources clearly show that the current Waiver capacity cannot meet actual need. For example, MDS data (which the UCLA project demonstrated underrepresented desire for discharge) shows that 20-25% of nursing facility residents prefer to live in the community. In San Francisco, TCM assessments conclude that approximately 80% of Laguna Honda

residents could leave if appropriate community services were provided and more than half of all residents would prefer community living.

Moreover, the State has applied for a federal Money Follows the Person grant, which contemplates providing home and community based services to as many as 2000 people over the next five years. The ability of the State to do so is contingent on the availability of Waiver services for these individuals. Thus, for California to make headway in meeting its *Olmstead* obligations it must reevaluate the ways it metes out its home and community based services and dollars. Expanding the NF A/B Waiver to meet a realistic projection of need would be one significant step in the right direction.

2. REALISTIC COST-CAPS: Even though nursing facility rates have increased significantly in the last year, the State has not increased the cost-cap for the NF A/B Waiver. Therefore, the NF A/B Waiver is still using a cost-cap from 2001 ($35,948), which is approximately $20,000 less than the average cost to the Medi-Cal program to keep someone in a nursing facility ($56,500). Limiting the cost-cap for the Waiver to $35,948 shows an unfair institutional bias, created by the state rather than the federal government, which results in people staying in (or going into) nursing facilities because they simply cannot purchase sufficient community based services for that amount.

   Recommendation: PAI recommends that the State appropriate funds for the NF A/B Waiver commensurate with the cost of nursing facility placement, and that such appropriation increase annually at a rate equal to any increases in facility rates.

3. FLEXIBLE ELIGIBILITY: Eligibility for the current Waivers is determined by a rigid "level of care" determination. This means that people who have specific needs that are not considered in the regulations defining each level of care (NF-A, NF-B, Subacute, etc.) are either denied Waiver services, or are placed at a lower level of care than they need to purchase a sufficient amount of services.

Recommendation: The Waivers need to allow for flexible eligibility determinations so that such individuals are not forced into institutions unnecessarily, or left at home with inadequate services.

4. AGGREGATE COST-CAP: Another way that the Waiver can meet the needs of people who need higher and lower cost services is by using an *aggregate cost-cap*. The NF A/H Waiver will have an individual cost-cap, which means that if a particular person has care needs that cost more than the cost-cap for his or her level of care, then he or she will be denied HCBS Waiver services. An aggregate, instead of an individual, cost-cap, would allow higher and lower cost recipients to balance each other out.

   Recommendation: PAI recommends that the State apply an aggregate cost-cap to the NF/AH Waiver to enable individuals whose costs exceed the cost for their designated level of care to benefit from HCBS Waiver services, rather than remain unnecessarily in institutions.

5. ALLOW FOR LOCAL ADMINISTRATION: Currently, the Nursing Facility A/B, Subacute, and Acute Care Waivers are administered by In-Home Operations at the Department of Health Services. One of the reasons given for the low number of slots is that IHO's staff is too small to administer a larger Waiver. Some other Waivers, like the MSSP and AIDS Waivers, are administered at the local level by community organizations and/or non-profit agencies. This allows for better contact with clients, local prioritization for slots, and program structure tailored specifically to the needs of particular communities.

   Recommendation: PAI recommends that the State allow for local administration of some or all Waiver slots to allow for better efficiency, local prioritization of slots, and tailoring of administration to meet local needs.

6. FIX WPCS/IHSS COORDINATION PROBLEMS: Since Waiver Personal Care Services were added to the Waivers in 2002, there has been a complete lack of coordination between this new attendant care Waiver service and the State Plan In-Home Supportive Services (IHSS) program. Despite the fact that funds were allocated to develop a seamless accounting system, the problems for recipients and workers have been so severe that some

individuals have opted out of the Waiver altogether. This is an unnecessary barrier which is within the State's control to resolve immediately.

Recommendation: PAI recommends that the State work with interested advocates and legislators to resolve this serious and unnecessary administrative barrier to seamless receipt of WPCS and IHSS.

7. TBI WAIVER: The State of California has no Waiver specifically for people with Traumatic Brain Injury (TBI). These individuals often have needs similar to people with developmental disabilities, but if their injuries occur after age 18, they are not eligible for those services. Thus, people with TBI are often left without adequate and appropriate services, as programs for individuals with TBI are extremely limited.

   Recommendation: The State should apply for a new HCBS Waiver to address the needs of people with TBI, as many other states have done.

8. IMPROVED QUALITY ASSURANCE: Consumers have expressed frustration about the level and type of oversight to the NF A/B and Subacute Waivers. In particular, they believe that the quality assurance component of the Waivers should be centered around consumers' satisfaction with their quality of life, their ability to hire and retain providers of their choice, and the amount of burden and stress related to coordination of their care. This is an important component to evaluate the success of any program and to determine where changes and improvements may need to be made.

   Recommendation: PAI recommends that the State develop and implement a quality assurance component to the Waivers, with the input of consumers and advocates, that is built on prior and current successful measures of life quality—both in and outside of California. Such a system should not be limited to level of care determinations and health and safety concerns, but should also include direct input from consumers, families, and supports about the individual's quality of life and satisfaction with his or her Waiver services. Evaluators must also be trained specifically on self-determination and other life quality factors.

9. SINGLE POINT OF ENTRY: Under the current system, individuals can easily be admitted to nursing facilities within a matter of days, but the process for

getting on a Waiver may take months, or even years. Other states have created a single point of entry system (sometimes called No Wrong Door), where people are evaluated for both Waivers and nursing facilities at the same time, and people are offered a choice. To do this, the State would need to allow for retroactive approval of Treatment Authorization Requests (TARs) for Waiver services, just as it does for nursing facility placement. Other states' programs have had a lot of success in helping people avoid placement in a nursing facility by approving and providing Waiver services just as quickly as institutional placement.

Recommendation: PAI recommends that the State implement a single point of entry system, and implement Welfare and Institutions Code section 14132.99(c), by developing a mechanism by which individuals who are referred for nursing facility placement will be informed about, and assessed for Waiver services in an expedited manner (3 days). Individuals who are determined eligible for and desire Waiver services will have their applications processed in an expedited fashion in order to avoid unnecessary nursing facility placement.

10. NEED TO COORDINATE NF WAIVER AND OTHER SERVICES FOR PEOPLE WITH DEVELOPMENTAL AND MENTAL HEALTH DISABILITIES: There is a lack of coordination between the various systems in California that serve people with physical disabilities, developmental disabilities, and psychiatric disabilities.

    Recommendation: There needs to be better coordination among these systems so that people who have a combination of disabilities can get the services they need from multiple systems working together.

11. CONSUMER-FRIENDLY MATERIALS AND OUTREACH: The Waiver application, assessment, and service determination processes are very complicated and consumer-unfriendly. Without an advocate or sophisticated family member present, many people do not understand the process or their rights in the process of applying for and receiving Waiver services.

    Recommendation: The State should create written information, both on its website and in print, that explains the process for getting on the Waiver, what services are available, how to find service providers, and consumers'

rights. DHS should also do outreach to individuals in institutions and hospitals to make sure that they know about HCBS Waivers and have an opportunity to apply for them. All information should be available in accessible formats and in other languages widely used in California.

Thank you for consideration of these comments. We look forward to Thursday's meeting and to further collaboration in this important effort.

Sincerely,

Elissa Gershon
Staff Attorney

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